



INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

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INVOLVING PATIENT AND FAMILY ADVISORY COUNCILS IN STAGES OF RESEARCH

STAGES	PFAC POTENTIAL ACTIVITIES	QUESTIONS FOR ADVISORS
Pre-Planning	<ul style="list-style-type: none"> • Identify meaningful research topics and potential questions. • Assist in prioritization of research questions. • Host community meeting to obtain broad input. • Assist in planning and facilitating a community health needs assessment 	<ul style="list-style-type: none"> • What matters to you and other patients/family members? • What would you like to know? • What would be most meaningful to you and other patients/family members to know about this topic/condition/diagnosis/care process?
Planning	<ul style="list-style-type: none"> • Review what is known and provide ideas for gaps in knowledge from a patient/family perspective. • Develop a set of questions to query patients/family members about challenges and solutions. • Advise on protocols and questions for surveys/interviews and provide input about planning interventions and selection of outcomes. • Review proposal and provide feedback. • Write a letter of support. • Review materials/forms for patients and provide feedback (e.g., information about eligibility and enrollment, informed consent, surveys/questionnaires). 	<ul style="list-style-type: none"> • What do we know now? • What would you like to know? • What would be most meaningful to you and other patients/family members to know about this topic/condition/diagnosis/care process? • How do different choices (e.g., treatments, medications, care processes) affect you? • What do you think might make patients hesitant to enroll in this study? • What information is critical for patients to know to decide whether or not to participate in study? • When is the best time to approach patients about enrolling in the study? • Do you have any concerns about the eligibility criteria
Pilot	<ul style="list-style-type: none"> • Review results and provide feedback for changes to study. 	<p><i>Note: Questions listed above in the Planning Stage are appropriate to use in this stage.</i></p>
IRB Approval	Not Applicable	Not Applicable

STAGES	PFAC POTENTIAL ACTIVITIES	QUESTIONS FOR ADVISORS
Data Collection and Enrollment	<ul style="list-style-type: none"> • Receive updates about enrollment progress and advise as needed. • Present updates about progress of research study to health care providers and patients/families/community. 	<ul style="list-style-type: none"> • How can we improve recruitment strategies to increase enrollment?
Analysis	<ul style="list-style-type: none"> • Discuss the interpretation of findings and the study's conclusions. 	<ul style="list-style-type: none"> • What do the results mean to you? • Do the conclusions reached by researchers make sense? • Is something significant being missed? • What will the findings mean to patients/family members? • Are questions left unanswered? • Does the study trigger additional questions to be studied?
Dissemination	<ul style="list-style-type: none"> • Create compelling and understandable summaries of research and findings for patients/families/community. • Identify organizational groups/committees and community groups that should be informed about study and findings. • Present findings to health care providers and patients/families/community. 	<ul style="list-style-type: none"> • Who needs to know about this study? • How do you find information to help you make decisions about your health care? • What are the best ways to inform patients/families/community? • How can patients/family members use these findings in shared decision-making with their health care providers?